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**Advocacy, Stress, and Quality of Life in Parents  
of Children with Developmental Disabilities**

by

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**A thesis submitted to the Department of Psychology  
in conformity with the requirements for the  
degree of Master of Arts**

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### Abstract

Research has consistently demonstrated that parents of children with developmental disabilities experience more stress than parents of non-disabled children (Beckman, 1991; Dyson, 1991). In order to face the challenges involved in raising a child with a developmental disability, parents must empower themselves by developing the skills to act effectively as advocates. However, little is known about the relationship between advocacy and family stress and quality of life. The purpose of this study is to determine the nature of this relationship through a qualitative analysis of parents' responses to a structured interview. Twenty-six primary caregivers of children with developmental disabilities were interviewed. Their responses were analysed using qualitative methodology outlined by Guba (1978) and Patton (1990). Advocacy was found to be related to both negative outcomes, involving increased stress and decreased quality of life, as well as positive outcomes, involving decreased stress and increased quality of life. Seven themes were found to be critical in determining the direction of the relationship. These themes include the parent's perception of the role of advocacy, the outcome of the advocacy actions, the relationship with professionals, the focus of the advocacy efforts, the effect on the parent's personal life, and the parent's personal feelings regarding their experiences as a parent of a child with special needs.

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## **Advocacy, Stress, and Quality of Life in Parents of Children with Developmental Disabilities**

Due to a recent emphasis on community integration of persons with developmental disabilities, researchers have acknowledged the need to focus on the unique experiences of parents of children with special needs ( Dyson, 1993; Frey, Greenberg, & Fewell, 1989; Minnes, 1988). When a child with a developmental disability is born into a family, the adjustment of the parents can be an extremely difficult process. Research has consistently demonstrated that parents of children with developmental disabilities experience more stress than parents of non-disabled children (Beckman, 1991; Dyson, 1991). It is generally acknowledged that, in order to face the challenges involved in raising a child with special needs, parents must learn to act effectively as advocates. Professionals often encourage parents to develop effective advocacy skills, and advocacy training programs such as “Partners in Policymaking” (Zirpoli, Wieck, Hancox, & Skarnulis, 1994) and “Tomorrow’s Challenge” (Hixson, Stoff, & White, 1992) are gaining in popularity. However, despite acknowledgement of the importance of advocacy to parents of children with special needs, as well as the promotion of advocacy by professionals, advocacy has rarely been studied in relation to parental stress and coping. In order to provide the best possible services to parents of children with developmental disabilities, professionals and researchers must be aware of the impact of advocacy on the parents’ lives. The purpose of the present study is to examine parents’ role as advocates in relation to feelings of stress and well-being.

A number of studies have focused on the ways in which parents try to cope with the difficulties that they face (Flynt & Wood, 1989; Cullen, Macleod, Williams, & Williams, 1991). These types of studies often focus on social support (Flynt, Wood, & Scott, 1992) and family

resources (Herman & Thompson, 1995), as well as on more general coping styles. Many researchers agree that parent characteristics are more important than child characteristics in predicting parenting stress, suggesting that interventions focusing on the needs of parents may have a greater impact on parenting stress than interventions which focus on the child (Beckman, 1991; Frey, Greenberg, & Fewell, 1989).

### Empowerment

Recently, services for families have begun to shift away from professionally-centred practices, in which family deficits are emphasized and the staff are considered to be the experts. Increasingly, programs are becoming more family-centred, aiming “to bring information, knowledge, skills and access to resources to families so that they may gain greater power over their own lives” (Dempsey, 1996, p. 7). Dempsey (1996) describes this as a shift toward enabling practices, which emphasize individual empowerment and focus on competencies, responsibility, knowledge, and a sense of partnership between the professional and the individual or family. In this context, empowerment refers to “. . . a process by which individuals gain mastery over their lives and a critical understanding of their environment” (Zimmerman, Israel, Shulz, & Checkoway, 1992).

Shultz, Israel, Zimmerman, and Checkoway (1995) conceptualize empowerment as a multilevel construct. Each level is relevant to the study of advocacy in its own way. At the level of individual or psychological empowerment, the concept refers to the individual’s ability to make decisions based on his/her knowledge of his/her own skills and resources. The second level, organizational empowerment, refers to organizations which provide opportunities for individuals to participate in decisions affecting resources in their environment. Community empowerment

encompasses the efforts of both individuals and organizations to shape the community in which they live. According to the authors, active participation in voluntary organizations, such as advocacy groups, may enhance individuals' perceptions of personal control. In turn, this perceived control is associated with improved health status.

According to Zimmerman (1995), psychological empowerment “integrates perceptions of personal control, a proactive approach to life, and a critical understanding of the sociopolitical environment” (p. 581). However, a “sense of empowerment” is not a concrete, measurable concept, and empowerment must be linked to actions and outcomes (Balcazar, Keys, Bertram, & Rizzo, 1996). Zimmerman (1995) differentiates empowered processes, in which people gain opportunities to increase their control over their own lives, from empowered outcomes, which are specific measurement operations. An empowering process refers to active efforts by the researcher to involve community members in aspects of research and perceive them as equal partners, to become part of the community, and to enhance the skills of the community members to decrease dependence on professionals. The principles of Participatory Action Research (PAR) exemplify such an empowerment perspective in research. In PAR, community members and researchers share their knowledge and skills to create social change in a way that will benefit the community. Empowering processes are considered to lead to empowered outcomes, which are composed of three main themes; mastery and control, resource mobilization, and sociopolitical context and participation. Although empowerment processes are difficult to quantify, because they refer more to the ways in which empowerment occurs, empowerment outcomes can be explored both qualitatively and quantitatively. In the current study advocacy will be examined as an empowered outcome measure of psychological empowerment.

Wehemeyer, Kelchner, and Richards (1996) consider the concept of “psychological empowerment” to be associated with self-advocacy behaviour. They describe psychological empowerment as being composed of individuals’ “beliefs that (a) they have the capacity to perform behaviors needed to influence outcomes in their environment and (b) if they perform such behaviors, anticipated outcomes will result” (p. 633). These beliefs are related to the person’s sense of personal efficacy, locus of control, and motivational factors. The authors argue that individuals must also have adequate self-knowledge regarding their own strengths and limitations. Individuals with high self determination, that is, the ability to make decisions free from external influences, are found to have a significantly more internal perception of individual control and tend to be more assertive than individuals with low self-determination. Parents who are advocates for their children are likely to possess these qualities of self-determination as important components to their sense of psychological empowerment.

Gallimore, Weisner, Kaufman, and Bernheimer (1989) examine family life and empowerment in relation to the ecocultural theory, which “construes families as more than hapless victims of implacable social and economic forces” (p. 217). Central to ecocultural theory is the notion of the ecocultural niche, which reflects the family’s material ecology (e.g., income, housing, transportation, services, etc.) and is also influenced by the cultural features which influence the meanings that people apply to their lives (e.g., beliefs and attitudes regarding morality, developmental disabilities, family life). This theory proposes that families adapt their ecocultural niche through changing socioeconomic constraints and as a result of family accommodation. They define accommodation as “the proactive social construction actions of the family to adapt, exploit, counterbalance, and react to many competing, and sometimes

contradictory forces” (p. 218). Semi-structured interviews with 102 families of children with developmental disabilities revealed that the construction and sustenance of a satisfying and coherent daily routine was a central theme in the lives of these families. These efforts by the family could both enrich the family routine as well as result in stress due to attempts to balance conflicting needs and resources. In sum, the ways in which parents struggle to balance their needs, resources, and constraints are crucial to their adjustment to the experiences involved in raising a child with a developmental delay. Parents who are advocates may experience more successes in this regard. However, their continued efforts to balance the contradictory forces in their lives may also result in increased stress.

### Advocacy

A number of researchers have begun to examine the role of parents as “advocates” for their child with a disability (Cunconan-Lahr & Brotherson, 1996; Balcazar, Keys, Bertram, & Rizzo, 1996). In his paper, Munro (1991) describes why advocacy, and more specifically advocacy training, has become such an important concept for parents of children with special needs. He writes that in this world of rapidly changing ideas and ideologies parents need to become “watchdogs” in regard to treatment philosophies and the implications of conservative fiscal policies. As well, Munro asserts that, while the influence of professionals over government policies has decreased, families are gaining leverage in regard to the practice of policymaking. Munro defines effective advocacy as “a non-violent empowerment and support process, through which families with disabled relatives can constructively express dissatisfaction and contribute to creative solutions to problems existing in human service systems” (p. 1). The results of Nachshen and Minnes’ (1997) qualitative examination of the experiences of parents of children with special

needs indicate that parents' feel that their role as "advocate" for their children is an important component of the coping response. Parents also often indicated a need to learn more effective skills in this regard.

The advocacy training program, "Partners in Policymaking," has been evaluated by a number of researchers regarding the effectiveness of the program in increasing the skills of parents to advocate on behalf of the needs of children with developmental disabilities. The program is designed to provide participants with the information and skills necessary to empower parents to obtain the services that they require to enhance their own experiences, as well as those of their child. The main components of this course include eight 2-day sessions with speakers who are experts in specific areas in the field of developmental disabilities, homework assignments encouraging a variety of advocacy actions, including attending community meetings and taking part in parent groups, as well as the completion of a major advocacy project. The results of a study by Zirpoli et al. (1994) indicate that the majority of the participants in the "Partners in Policymaking" evaluated the program favourably and felt that it was effective in teaching them to be a better advocate. After the course, the majority of participants had performed advocacy actions, including efforts to influence public policy through meetings with public officials and efforts to educate the public through the use of the media and presentations at meetings and conferences.

Balcazar et al. (1996) present a taxonomy of advocate development in order to determine the effect of advocacy training on the actions of individuals at various stages of advocacy development. The authors used baseline data regarding the advocacy activities of 24 participants to separate them into three groups. Members of the "Beginner" group belonged to one

organization but were passive members, received few services, and performed less than three advocacy actions during the nine months prior to the beginning of the study. Members of the “Involved” group belonged to at least one organization of which they were an active member, obtained services as needed, and performed from three to ten advocacy actions to address personal needs during the last nine months. “Activist” individuals belonged to several organizations at local and state levels in which they held leadership roles, obtained services for local group members, and had performed more than ten actions during the last nine months. The results indicate that, although advocates at all levels benefited from advocacy training, individuals in the three groups benefited differently. For example, individuals in the “Activist” group benefited the most from this training, probably due to the fact that they are the most likely to have more skills and a greater number of contacts than individuals in the other groups. “Beginners” were more likely to take the initial steps toward joining organizations and demanding more services. The authors suggest that it may be important to tailor advocacy training programs around individuals’ previous experience with advocacy.

Although these results support advocacy as beneficial to parents of children with disabilities, they do not directly depict the relationship between advocacy and stress and/or quality of life. Nachshen and Minnes (1997) proposed that parents do employ the actions and attitudes of the advocacy movement as a means of coping with stress. Twenty-six parents of children with special needs were asked open ended questions about the challenges they faced in dealing with 17 issues across the lifespan. Parents were also asked to describe their successes and to discuss how they achieved these successes. A thematic analysis of the responses indicated that parents coped with challenges using three main techniques: (A) Persistence: “We just do what we have to for

our son, and if other people don't understand that, then we don't waste our time on them." (B)

Focusing on the Positive: "I keep him clean and well-dressed, love him with all my heart. And we take him everywhere we go. . . . I feel by doing this, others may think he's a worthwhile human being." (C) Education and Information Seeking: "I tell my doctors things they didn't know."

Persistence, focusing on the positive, and education and information seeking can be regarded as integral to the role of an advocate.

While parents do employ advocacy strategies in order to meet the challenges they face in raising a child with developmental disabilities, it is unknown whether or not the role of advocate is related to decreased stress and an increased sense of well-being or quality of life. If there is a relationship, the mechanisms underlying that relationship are equally obscure. McCubbin, Thompson, and McCubbin (1996) proposed a Resiliency model of family adjustment and adaptation which posits that a family's reaction to crises depends on their ability to employ positive behaviours to maintain the family unit and the well-being of individual family members. In this model:

The Stressor and its Severity interact with the family's Vulnerability, which is shaped by the pile-up of family stresses, transitions, and strains occurring in the same period as the stressor. Family Vulnerability interacts with the family's typology, which is the Established Patterns of Functioning. . . . These components, in turn, interact with the family's Resistance Resources. . . . This, in turn, interacts with the family's Appraisal of the Stressor. . . . The family's Appraisal interacts with the family's Problem Solving and Coping Strategies. . . . (p. 16)

This model suggests that advocacy may act on the family's resiliency to stress at three levels.

First, the advocacy role may be integral to the degree to which families obtain resistance resources such as social support and their ability to obtain resources in the community. Advocacy may also serve to affect the family's appraisal of the stressor, through their degree of self-efficacy, and belief in personal control. Another place where advocacy may cause change is with the family's ability to solve problems and cope with stress through the specific coping mechanisms employed by the family members.

One way in which advocacy might affect parental stress is through the increased social support that comes from being part of a network of parents/advocates. Intagliata and Doyle (1984) submit that self-help (advocacy) parent groups may be popular because of the social support provided by "a very special group of others all of whom share the same types of stress and burden as they do" (p.6). The Interpersonal Problem Solving Skills training program was effective in increasing social support in parents of children with disabilities. Interestingly, the authors found that the parents' focus on the needs of their child with a disability can sometimes impede their abilities in relating to other individuals unconnected to the world of developmental disabilities. This finding has some interesting implications regarding the relationship between advocacy and stress. Perhaps parents whose major life focus centres on advocating for the needs of their child with a disability have increased stress in relation to their own interpersonal issues.

The work of other researchers also presents social support as a mediating variable in the relationship between advocacy and stress. Flynt and Wood (1989) asserted that a higher level of coping strategies centred on obtaining social support may help to explain their finding that black mothers of children with special needs had lower levels of stress than white mothers, and older mothers had less stress than younger mothers. The authors suggest that black mothers and older

mothers may have more well-developed social support network than mothers who are white and/or younger. Parents themselves acknowledged a strong social support network as a support for advocacy behaviour in their lives (Cunconan-Lahr & Brotherson, 1996).

Another possible mediator in the relationship between advocacy and stress is the greater service usage observable in those individuals who are more involved in advocacy behaviour. Balcazar et al. (1996) utilized the number of services received as a means of taxonomizing participants into one of three advocacy groups (Beginner, Involved, Activist). The authors suggest that "Activists become more knowledgeable about the network of services available to them and gain more access to those services" (p.350). The ability to obtain more services may help to buffer the degree of stress in the lives of families of children with developmental disabilities.

Parents' positive beliefs regarding their own ability to handle challenging events effectively has been shown to be related to decreased levels of parenting stress. Research regarding the self-advocacy of individuals with developmental disabilities has highlighted the importance of self efficacy and locus of control as characteristics of individuals exhibiting self-determined behaviours (Wehmeyer et al., 1996). Krauss (1993) found that an internal locus of control, that is, the parents' feeling that the control over the outcome of events lies within their own hands, was a significant predictor of decreased stress in both mothers and fathers. A study by McKinney and Patterson (1987) of 67 mothers of children with disabilities found that mothers who had a high degree of perceived control obtained decreased scores on measures of stress. A surprising interaction was found between perceived control and spouse support in that mothers with high control and low spouse support obtained significantly higher scores on measures of stress.

Advocacy may also reflect an approach to coping that helps parents to achieve a more successful adaptation to stressful situations. Frey, Greenberg, and Fewell (1989) demonstrated that parents' positive beliefs regarding their coping efficacy is highly correlated with decreased parenting stress. In the same study, the Problem-Focused Coping and Seeks Social Support scales of the Ways of Coping Checklist were significantly related to lower levels of psychological distress. The authors assert that "the most effective interventions for parenting stress might target the development of self-enhancing comparative frames of reference and cultivate greater perceived control on the part of parents" (p. 248).

One of the reasons why advocacy and empowerment have rarely been studied in relation to stress and quality of life relates to the lack of consensus regarding the use of the terms as psychological research constructs. All of the studies regarding empowerment provide different definitions and key components. In their article aimed at clarifying the concept of empowerment as an outcome of disability service, Dempsey and Foreman (1997) summarize some of the key components of empowerment as they relate to the delivery of family services. One component is self-efficacy, which is the belief that one will be able to effect some change through one's actions. Empowering services are those in which the parents' sense of self-efficacy is enhanced. Another component is participation and collaboration, reflecting a sense of partnership between parents and professionals, which is emphasized in empowerment models of family service delivery. A sense of control is also a key concept in discussions of empowerment, relating to parents' attributions of change to their own actions. A fourth component is parents' ability to determine their own needs and receiving appropriate support from professionals in selecting the best methods of meeting their needs. Empowering services are ones which provide parents with an

understanding of the environment and an ability to effectively utilize available resources and sources of support. Personal action may also be emphasized, as well as increased access to resources.

To date, many of the explorations of the process of empowerment have involved qualitative inquiries. A qualitative study on the process of empowerment by Lord and Hutchison (1993) explored a number of the concepts outlined above. The authors investigated the life experiences of 41 men and women (including some from the disability movement) who had experienced powerlessness in their lives, but had exerted efforts to increase feelings of control over their own circumstances. The authors describe a number of factors which the participants indicated as the main impetus for change in their lives. First, being involved in a crisis or life transition prompted participants to critically evaluate their situation. Those who had a strong sense of self-efficacy, as well as social support, responded most favourably to these transitions. In disability literature, the birth of a child with a developmental disability is seen as the main crisis. However, challenges are present in almost every stage of normative development, especially when expected developmental milestones are not met. Change also occurred in response to feelings of anger and frustration when needs were not being met. While some participants remained stuck in the anger phase for a period of time, others allowed their anger to fuel action. Having and responding to new information was also presented as a major mobilizing force. A major concept of advocacy is the ability to access information, which in turn can lead to increased personal resources for families. Finally, participants aimed to build on their inherent strengths and capabilities. Those who succeeded attributed their empowerment to their own abilities, demonstrating the importance of self-efficacy. Other important components of empowerment

included social support, access to resources, and participation.

Scorgie, Wilgosh, and McDonald (1996) explored the concepts of advocacy and empowerment in their examination of how parents of children with special needs manage life successfully. The authors presented a thematic analysis of a qualitative inquiry into three main aspects of family life: What are the strategies used by parents, what are the personal attributes or abilities that characterize successful coping, and how are parents transformed through their experiences? The themes that emerge from this inquiry reflect some of the issues presented thus far, and suggest a possible link between advocacy and stress. Parents' discussions of the strategies that they use to achieve successes in their family's lives are most indicative of the role that advocacy might play in helping parents to increase their quality of life. Positive personal reframing emerged as an important strategy used by parents to manage life when a child has a disability. This includes acceptance of the child, a strong determination to succeed, an ability to make meaning of events, competence and self-confidence, and the ability to live with indeterminacy. Another life management strategy is the maintenance of a balance within the individual's roles and responsibilities. Sub-themes in this strategy include the nurturing of the self, the spouse, and the other children, as well as a focus on balancing the roles of teacher and advocate with that of being a parent. One central issue in this theme was the parents' feelings about being an educator to society about individuals with disabilities, specifically their own child. A third theme of effective life management concerns the parents' ability to meet the needs of their family through their use of resources. Parents spoke of the need to gather information, collaborate productively with professionals, initiate and maintain contact with other parents of children with disabilities, and utilize other important sources of support.

In their discussion of the relevance of these themes to the study of families of children with developmental disabilities, Scorgie, Wilgosh, and McDonald (1996) proposed some directions for future research. The authors emphasize the importance of research regarding parents' ability to reframe negative events in a more positive and manageable way. This may relate to the advocate's ability to create new meanings and positive future directions for their families when faced with a crisis. They also discuss the importance of parents' determination to succeed in the face of negative events, a quality necessary to the advocacy role. Self-confidence, competence, and self-esteem are viewed to be directly related to personal success, as is a strong sense of personal control. They also emphasize the importance of a sense of hope for the future, especially when that hope is invested in an attainable goal.

The bulk of literature regarding empowerment suggests that, through increased social support, increased access to resources, feelings of self-efficacy and belief in personal control, as well as more well-developed coping mechanisms, the advocacy role is likely to be related to decreased feelings of stress and increased quality of life. However, the advocacy role may not be entirely beneficial to parents. Research suggests that increases in the self-advocacy behaviour of individuals with disabilities may create new challenges for families, thus increasing stress (Mitchell, 1997). It is important to consider whether or not this relationship can be extended to describe the impact of parental advocacy on families. That is, could parents who act as advocates for their child with special needs face increased stress in some areas of their lives? The testimony of parents suggests that this may be the case. Kate McAnaney (1990) writes, "I do not like being typecast as pushy, bitchy, argumentative or as the mom-everyone-wants-to-hide-from, but I have been called all of those things. And it hurts sometimes. It makes me feel uncomfortable,

embarrassed, annoyed or invalidated” (p.20). The paradoxical nature of the relationship between advocacy and stress is highlighted by the fact that McAnaney also speaks of her role as an advocate with great love and optimism. Parents interviewed by Scorgie, Wilgosh, and McDonald (1996) also spoke of the difficulties of advocacy. They reported a feeling of being burdened by the responsibilities of this role and feel that professionals can sometimes place inordinate expectations on them to fulfill this role. It is suggested that the role of teacher and advocate can sometimes detract attention from parents’ primary role, which is to simply be a parent to their child.

Cunconan-Lahr and Brotherson (1996) explored the paradoxical nature of advocacy by interviewing participants in an advocacy training program, “Partners in Policymaking.” Through a qualitative analysis of information obtained in these interviews, the authors identified themes in relation to the supports and barriers for successful advocacy. The supports include (1) Empowering Our Voices (i.e., “how,” “to whom,” “what,” and “when” to communicate), (2) Networking With Others (i.e., with partners and community members, as well as policymakers), and (3) Attitudes of Courage and Leadership (i.e., personal characteristics, such as self-confidence, risk taking, etc., and family and friends). Barriers to advocacy include (1) Who Has the Time? (i.e., not enough time, balancing time with family members, and lack of pacing, leading to “burnout”), (2) Advocacy is Expensive (i.e., advocates are volunteers, hidden costs, and costs for personal supports), and (3) Emotions Can Get in the Way (i.e., telling one’s story, emotional sharing by fathers carries social stigma, and fears of empowerment). The authors conclude that the advocacy role itself represents a state of ambivalence, in which barriers must be considered along with supports in the facilitation of the advocacy role. It follows, then, that the relationship between advocacy and stress and well-being may not be as direct as it may seem.

An exploration of advocacy by Nelson, Howard, and McLaughlin (1993) provides some insight as to why advocacy may result in increased feelings of stress for parents. They suggest that a true sense of partnership between parents and professionals is not a current reality, but remains in development. They assert that, while some parents have been able to immerse themselves in the role of collaborator, some professionals may be unprepared to deal with the “parent-as-expert.” A sense of resentment may build in situations when parents are unable to discriminate between “what is legally their right and what privileges go beyond the scope of their power” (Nelson, Howard, & McLaughlin, 1993; p. 64). The authors also suggest that exercising legal rights involves a necessary expenditure of personal resources, which may strain the parent’s abilities or exclude those whose resources are limited. As well, the philosophy of participation may impart feelings of guilt to parents who are unable to meet the demands of the role of collaborator. Finally, parents may find it difficult to don the mantle of professionalism, a role for which they may be completely unprepared. The complexities involved in delivering services in a manner that is consistent with the empowerment model may contribute to a relationship between advocacy and feelings of increased stress and decreased quality of life.

As the need for parents to become advocates for their children with developmental disabilities becomes increasingly apparent, and the empowerment model is considered to be the ideal model of service delivery, researchers have begun to champion advocacy training as an important intervention technique. While the results of some studies have suggested relationships between advocacy and other areas of family life, none has examined these variables directly. In order to provide the most effective interventions for parents of children with special needs, professionals need to be aware of the impact of parental advocacy on family stress. The purpose

of this study is to describe the relationship between advocacy and stress and quality of life.

## Method

### Participants

Agencies serving the needs of individuals with developmental disabilities in Thunder Bay, Ontario, were contacted, and agreed to inform parents about the nature of the study. These agencies included Avenue Two, Options Northwest, Lakehead Regional Family Centre, and Wesway. Contacts were also made with a neuropsychiatrist serving the special needs community, as well as the Autism Society. The study was also advertised in the Thunder Bay newspaper and on community television. Interested participants were encouraged to contact the researcher to obtain the questionnaire and arrange a time for an interview. Both mothers and fathers were invited to participate, provided that they considered themselves to be actively involved in the care of their child. Participants included 25 mothers and 1 father of 26 children with developmental disabilities. The participants had a mean age of 40 ( $SD = 11.6$ ). Forty percent of the participants had a College or University degree, 38.5% had a high school diploma, one parent had not completed high school, and another declined to respond. The majority of the participants were married (69.2%). The others were either separated (11.5%), single (7.7%), divorced (7.7%) or widowed (3.8%). The children had a mean age of 13 ( $SD = 10.1$ ) and were distributed between males (57.7%) and females (42.3%) in a manner consistent with the greater number of males with disabilities in the population. The majority of the children had been diagnosed with Autism (34.6%), Down Syndrome (15.4%), a developmental disability due to other causes (23%) or developmental disability due to unknown causes (26.9%). The majority of the children continued to live at home with their parents (73.1%).

## Measures

### Demographic Information

1) A family information checklist was used to obtain demographic information regarding parents age, sex, education, and marital status and the child's age, sex, type of disability and living accommodations (see Appendix A).

### Family Stress

2) The Family Stress and Support Questionnaire (FSSQ; see Appendix B) was developed by the current author (Nachshen, 1996; Minnes & Nachshen, 1998) and revised by Woodford (1998), and is used as a structured interview. The FSSQ was derived from issues raised by a focus group of parents of children with Fragile X Syndrome. The questionnaire covers 24 issues that may occur in families caring for a child with a developmental disability. These issues include (1) the diagnosis of your child as having a developmental disability, (2) seeking a second opinion, (3) explaining to others about your child's disability, (4) feelings about the cause of your child's disability, (5) dealing with friends/family/people in the neighbourhood on a day-to-day basis, (6) dealing with doctors and other allied health professionals, (7) dealing with legal professionals, (8) dealing with your child's teachers and the educational system, (9) creating and/or finding opportunities for your child to make friends and participate in activities, (10) choosing the best level of integration for your child, (11) making the decision concerning accommodation in the home or in the community, (12) meeting the needs of other children in the family, (13) meeting your own personal needs, (14) meeting the needs of your spouse or partner, (15) maintaining satisfying friendships for yourself, (16) dealing with your child's sexuality, (17) work placements or employment for your child, and (18) long-term planning for accommodation for your child,

(19) planning for wills, trusts and guardianships, (20) planning for emotional and social support for your child, (21) transportation, (22) day-to-day assistance with care of child, (23) time apart from your child, and (24) dealing with financial issues. Participants are initially asked to rate the stressfulness of each issue. Within each issue, respondents are be asked to describe the challenges they have faced, the successes they have had, coping strategies used and to share any suggestions for how situations could be made easier. They are also asked about any recent changes in stress for that issue and to explain why these changes occurred.

#### Other measures

A number of measures were included in a questionnaire package that was completed by the participants prior to the interview. The package consisted of a number of quantitative questionnaires which could not be analysed appropriately due to the small sample size of this study. The data obtained from these questionnaires will be used in a future quantitative examination of the relationship between advocacy and stress and quality of life, when enough data has been collected to permit the use of multivariate statistical techniques.

#### Procedure

Parents of children with developmental disabilities contacted the researcher to indicate that they were interested in participating. Individuals who wished to participate were asked to sign a consent form. When they had given informed consent to participate, they were given a package of questionnaires, which they were asked to complete in their own time. When the participants completed these questionnaires, they contacted the researcher who met with them to discuss any questions they have in regard to these questionnaires. At this point, the researcher conducted a standardized open-ended interview. This type of interview is designed to follow a structured

format and is considered to increase internal reliability through minimizing interviewer effects and removing differences within the interview as a source of variation in responding (Patton, 1990). Participants were informed that the purpose of the interview was to discuss the relationship between advocacy and stress and quality of life. The definition of advocacy (Munro, 1991) was given to them and they were instructed to consider the questions as they related to their life within one year prior to the interview. The interview followed the questions outlined in the Family Stress and Support Questionnaire. A stance of empathic neutrality, which is a commitment to “be true to complexities and multiple perspectives as they emerge” (Patton, 1990; p. 55) coupled with a sense of empathy and understanding to the feelings of the interviewee, was taken by the researcher in response to all experiences shared by the participants. These interviews were audio-taped to ensure that participants’ statements were accurately transcribed. After the interview was complete, parents were offered the opportunity to discuss any issues that they felt had not been covered in the interview. The participants were thanked for their time, and given compensation for costs incurred during the interview. Recordings of the interview were transcribed by a fourth year honours student.

### Data Analysis

The interview transcripts were examined for statements regarding the relationship between advocacy and stress and quality of life. Only these statements were used in further analysis. Examination of the data included a brief case analysis, in which each individual participant’s responses were examined to extract statements regarding advocacy and its relationship to stress and quality of life for each individual. As well, a cross-case analysis was performed in order to group together statements from all participants according to the topic being discussed. Two

techniques were used to synthesize the data into themes. A process-outcome matrix (Patton, 1990) was used to organize all statements relating advocacy to stress and quality of life into four categories, which were then submitted to a thematic analysis. This technique allows the researcher to organize the qualitative information into processes and outcomes, enabling an understanding of the “linkages, patterns, themes, experiences, content or actual activities that help us to understand the relationships between processes and outcomes” (Patton, 1990; p. 416). Once the process-outcome matrix was complete, the data were then converted into systematic categories through an examination of the recurring regularities representing patterns (Guba, 1978). To increase reliability, the researcher examined the categorizations for internal homogeneity, which concerns the degree to which the data composing a theme converge meaningfully, and external heterogeneity, which concerns the degree to which the differences between categories are clear (Patton, 1990). The categories were prioritized according to the “salience, credibility, uniqueness, heuristic value, feasibility, special interests and materiality of the classification schemes” (Patton, 1990; p. 403). An effort was made to examine the categories for completeness based on the methods described by Guba (1978). The first criterion of completeness regards the extent to which the categories are internally consistent and comprise a holistic view of the phenomenon when viewed externally. The second criterion involves the inclusiveness of the categories to the available data. There should be minimal data that cannot be assigned to the categories that are created. The third criterion involves the use of another competent judge to ensure that “a) the categories make sense in view of the data which are available, and b) the data have been appropriately arranged in the category system” (Guba, 1978, p. 56-57). The only criterion of completeness that was not examined in this study is the extent to which the qualitative analysis

and emergent themes are credible to the participants in the study. The degree to which the participants agree with the categorization of themes will be examined in a future research endeavour.

### Results

Analysis began with a brief case analysis of parents' responses to the FSSQ. This was done in order to examine the distribution among participants of statements regarding the relationship between advocacy and stress and quality of life. The results of this analysis indicated that all parents offered comments relating advocacy to both decreased stress and increased quality of life as well as increased stress and decreased quality of life. At times, both extremes could be found within the same sentence. There was not a single participant whose statements about advocacy fell only at one end of the continuum.

A process-outcome matrix was created to organize the qualitative data according to two dimensions. The process dimension related to whether a statement reflected an acceptance or an obvious rejection of the use of advocacy. This was determined through the parents' statements regarding their use of advocacy, or comments clearly indicating a decision to refrain from involvement in advocacy. The outcome dimension related to the resulting effect of the process on stress and/or quality of life. The fit of the data within each category was judged through an case analysis of the parents' other statements regarding the issue being discussed. A determination was made regarding categorization through careful inspection of ensuing comments, indicating the effect of the advocacy actions on stress, well-being, or quality of life. A comment was judged to be related to a positive outcome if participant had clearly related his/her acceptance or rejection of advocacy to a decrease in stress or an increase in quality of life. For example, a statement was

judged to be related to a negative outcome if the participant had clearly linked his/her acceptance or rejection of advocacy to an increase in stress or a decrease in quality of life. Each quadrant of the process-outcome matrix was submitted to a thematic analysis in order to synthesize the content of the statements. The resulting matrix and themes are presented in Table 1.

#### Use of Advocacy, Positive Outcome

This quadrant contained the most statements in the matrix. A thematic analysis of the statements relating advocacy to decreased stress and increased quality of life revealed the following themes:

##### **(1) Advocacy is a Coping Strategy**

Many parents made statements indicating that they used advocacy in order to handle a variety of challenging situations, including dealing with professionals, the education system, and achieving their desired level of integration. When asked how she coped with the challenges of integrating her son in the school system, one mother responded “I keep going higher and higher. If the teacher is not going to do it, I go to the board and talk to people until someone listens to me and helps me out.” Another parent created an advocacy and support group for parents of children with Autism in order to cope with her own stresses relating to having a child with special needs.

##### **(2) Effecting Positive Change through Advocacy**

Many parents spoke proudly of the changes that had occurred in their lives as a direct result of their advocacy. Some parents spoke of the improvements that had occurred in their children’s functioning. One parent said: “If I hadn’t been a strong person he would be at a very different place today.” Other parents told of the changes they had effected in the community. One

Table 1

**Process-Outcome Matrix of Statements Relating Advocacy to Stress and Quality of Life**

Outcome		
Process	Positive Outcome	Negative Outcome
Use of Advocacy	<ol style="list-style-type: none"> <li>1. Advocacy is a Coping Strategy</li> <li>2. Effecting Positive Change</li> <li>3. Becoming Informed</li> <li>4. Educating Others</li> <li>5. Obtaining Services</li> <li>6. Gaining Support</li> <li>7. Cooperation with Professionals</li> <li>8. Advocacy Increases Feelings of Confidence and Empowerment</li> <li>9. Plans for the Future</li> </ol>	<ol style="list-style-type: none"> <li>1. Advocacy is a Challenge</li> <li>2. Advocacy Involves a lot of Legwork and an Overload of Responsibilities</li> <li>3. Professionals React Negatively</li> <li>4. Coming up Against Brick Walls</li> <li>5. Advocacy can only be Accomplished at the Expense of one's Personal Life</li> <li>6. Personal Feelings Make it Difficult to Advocate</li> </ol>
Rejection of Advocacy	<ol style="list-style-type: none"> <li>1. Don't Dwell on the Past</li> <li>2. It is a Waste of Time to try to Convince People Who Don't Listen</li> <li>3. Taking Time for a Personal Life</li> <li>4. Pulling Back from Involvement and Letting Others Take Over</li> </ol>	<ol style="list-style-type: none"> <li>1. Hopelessness about the Future</li> <li>2. Giving up on Professionals and Services</li> <li>3. Feelings of Guilt and Fear</li> </ol>

parent, who felt a great deal of stress regarding the diagnosis of her child, said, “It was most stressful that I didn’t get the information all at once. We’ve made a package through the Autism Society that explains everything, so we’ve already changed things.” Another told of the improvements in the attitudes of doctors and professionals, stating “There is more professional awareness of the needs and wants of special populations. Parents won’t just believe doctors. They love their kids and won’t just accept anything.”

### **(3) Becoming Informed through Advocacy**

The process of advocacy requires an awareness of the socio-political environment and demands an understanding of the needs of individuals with developmental disabilities. Parents frequently credited advocacy with enabling them to obtain information crucial to their own understanding of their family situation. One parent credited a decrease in stress related to her feelings about the cause of her child’s disability to the information she had obtained through participation in various workshops or seminars. One parent said, “We’ve been reading and checking out other cities where parents have taken initiatives to create jobs for their children, and this gives us hope.”

### **(4) Educating Others through Advocacy**

A number of parents credited successful outcomes to the education of others. Many parents felt that one of their primary responsibilities as advocates for their child was to educate the people in their community, including professionals. One parent said “Anyone who has any dealings with him we are to educate.” Another parent credited a decrease in stress to her role as “being a person who shares this experience with others.” One mother who coped with the stresses of dealing with family, friends, and people in the neighbourhood by talking and answering

questions, explained that “More knowledge and understanding leads to less fear and more acceptance,” and credits a decrease in stress to the fact that “more people are getting to know her and watch out for her. They have more tolerance and are more understanding.”

#### **(5) Obtaining Services through Advocacy**

Advocating for the needs of their children with special needs helped parents to obtain necessary services, improving their feelings of well-being. A number of parents credited advocacy with allowing them to access the services they needed, thus decreasing their levels of stress. One parent reported that a success in planning for long-term accommodations was the fact that “he got on the Avenue Two list when he was out of school. The squeaky wheel gets the oil. I called them every week.”

#### **(6) Gaining Support through Advocacy**

An important component to the advocacy role is the support provided by other parents who are facing similar challenges. This theme emerged strongly in parents who were part of an advocacy related organization or group. One parent experienced a decrease in stress because “I don’t feel as alone. I am more in control. I have the help and support of other parents. We exchange information.” This feeling was echoed in another parent who credited her successes to “support groups. Being with people in the same boat and sharing information and knowledge.”

#### **(7) Cooperation with Professionals**

The relationship between advocacy and well-being was facilitated through a sense of cooperation with professionals in the fields of medicine, education, law, and services for individuals with developmental disabilities. In response to a perceived ignorance on the part of medical professionals, one parent dealt with it by “Being honest with the doctor regarding

concerns about health. Interaction with the doctors was very good. I was sent in to other professionals. You have to advocate.” Another spoke of the challenges of dealing with the education system. “It has been a struggle, but they finally seem to be listening to me more. . . . It is just a matter of changing a couple of people to see what he needs. The majority of the workers are on the same wavelength as me.”

#### **(8) Advocacy Increases Feelings of Confidence and Empowerment**

Parents who related advocacy to well-being spoke about the feelings of self-efficacy that are central to effective advocacy. Many comments related parents’ confidence in their abilities to improve their and their families’ quality of life. One parent described why she used advocacy to resolve a problem relating to transportation: “It makes me feel better to let them know I’m not going to be pushed around.” Another parent said, “every time you do it you become more confident.”

#### **(9) Plans for the Future**

Advocacy related to positive outcomes tended to involve active planning for future inevitabilities. When speaking of future events such as wills and guardianships, long-term accommodations, and long-term care, parents related a sense of comfort derived from advocating for a specific plan. One parent said, “I have spoken with other parents who have the same feelings. We plan to come together to privately purchase a home when our kids are older.” This parent related this planning to “a decrease in stress because we are keen on the idea of buying a home and we are not alone.” When asked about successes, another parent responded, “doing something about it. Planning for the future with the Autism Society. As a society our goal is to make sure there is proper housing. It is a success to have a goal.”

### Use of Advocacy, Negative Outcome

A thematic analysis of the statements relating advocacy to increased stress and decreased quality of life revealed the following themes:

#### (1) Advocacy is a Challenge

Some parents perceived the job of advocacy to be a challenge in and of itself. The need to advocate for their child was often reported as a stressor. One parent said, "I had to fight for him all the time. It was always proving instead of people just believing me." Another parent said that a main challenge was "fighting like crazy. If you don't fight, they'll just get her out of their way."

#### (2) Advocacy Involves a lot of Legwork and an Overload of Responsibilities

Participating in advocacy is a lot of work for parents who already have other responsibilities such as work and raising their family. The philosophy of "parents-as-experts" was found to be difficult for one parent, who commented, "They expect me to do an educational plan and it is not my job. . . . They expect an awful lot." Many parents resented having to add advocacy to an already large list of responsibilities. One parent said, "I've had to quit my jobs to look after him. It was too stressful working and having to leave to go to school for him and look after him. I feel like I'm being pulled in different directions and there are days when I lose who I am. I find it hard to meet everyone else's demands and still have time for myself." Another parent's comment highlighted the role of responsibility overload in the relationship between advocacy and increased stress, stating, "I thought I was supermom, which didn't work. . . . I eventually had a breakdown, requiring medication. I was overloaded with stress and anxiety."

#### (3) Professionals React Negatively to Advocacy

While some parents viewed professionals as partners, others viewed them as adversaries

who react defensively to their advocacy efforts. One parent spoke about a battle for her child to be diagnosed: "I feel that mothers know. It got to the point that the doctors called me a neurotic mother. I insisted on double and triple checkups." Another parent, facing challenges in the school system, reported that her child's teacher "treats me as a spy and doesn't want me in the classroom."

#### **(4) Coming up Against Brick Walls**

Another theme that emerged in the relationship between advocacy and negative outcomes was the feeling of the parents that they kept coming up against brick walls. One parent who actively advocated for her child's inclusion in community activities reported "Even though I've sent home packages it doesn't seem to make a difference." Another commented "We have children who have needs and parents who have needs, but there is no more money in the system to help, so we're left to our own devices."

#### **(5) Advocacy can only be Accomplished at the Expense of one's Personal Life**

While most parents regarded advocacy as a necessity of life, many commented that it was often accomplished at the expense of fulfilling their personal needs. Trips to conferences and workshops and time out for meetings often decreased the time for parents to spend with friends and family, or to simply meet their own personal needs. One parent said "I don't have enough time in between meetings, assessments, behaviour modification, and occupational therapy. I often have to fight just to find a half-hour." Another parent commented "He became my priority. Everything else came second, including my marriage. He took over my life for a long time."

#### **(6) Personal Feelings Make it Difficult to Advocate**

**It was not uncommon to note responses suggesting feelings of depression and anxiety in**

relation to caring for a child with special needs. Parents often reported that these feelings made it difficult for them to advocate for their children. One parent commented that advocacy was stressful because “I don’t like getting excited and thinking it is going to work and then it doesn’t.” Another remarked poignantly, “People see this beautiful, bright, happy looking face, but as soon as she asks a question I feel that I have to explain for her. . . . It really gets to me because I wish that she were more normal. Her condition is so unexplained that I don’t understand it myself, so how can I expect someone else to understand the delays? It’s upsetting when people say that you would never know that there is something wrong with her, because I wish there wasn’t anything wrong with her.”

#### Rejection of Advocacy, Positive Outcome

A thematic analysis of the statements relating a rejection of advocacy to decreased stress and increased quality of life revealed the following themes:

##### (1) Don’t Dwell on the Past

A lack of advocacy was related to a positive outcome in situations where parents had made a conscious decision not to engage in advocacy in regard to issues that had happened in the past. One parent spoke of her feelings of dealing with the cause of her child’s disability: “(I feel) a lot of anger. It was negligence on the part of the doctor. But we are past it. It is not worth it.” This parent reported that her feelings of stress had “Decreased. Just the realization that it doesn’t make a lot of difference.” For many, choosing not to advocate on behalf of past issues allowed them to focus meeting more current challenges. One parent dealt with stress related to the diagnosis by putting it “to the back of my head. . . . I can’t dwell on it all of the time because it will make me crazy and screw my life up. I have more important things to deal with.”

## **(2) It is a Waste of Time to try to Convince People Who Don't Listen**

While many parents felt it was important to educate others, and felt that they were successful in doing so, a number of comments were made indicating that parents felt that it was a waste of their time to try to educate people who were not going to listen or change their minds. Many parents indicated that they chose individuals to whom they would offer explanation, and ignored others. One parent commented that she had experienced a decrease in the stress related to explaining to others because "I don't care. People are going to think what they want. I'm not going to knock myself out to change them and they just won't see us. It's their loss. He's just a funny kid." Another parent said, "Why should I devote all of that time to something that is not going to work when I could spend my time on him?"

## **(3) Taking Time for a Personal Life**

Decreasing participation in advocacy activities allowed some parents to reclaim aspects of their personal life. An overworked mother said, "I couldn't complete housework and things like that because I was so busy with volunteering and doing extra activities. I was finding that I was working full days, but volunteering. It was almost like getting away. I don't know what I was doing. I don't know if it is a running away or finding a cure or doing all I can do, but I wasn't. It seemed like I totally lost control." The same mother discussed how her life had recently begun to change: "Stress has decreased, because I cut back on volunteering. I started an exercise program." Another parent advised, "If you have a child like that your life need not be consumed by it. Life has to go on."

## **(4) Pulling Back from Involvement and Letting Others Take Over**

This theme was especially relevant to the older parents whose children were living outside

of the home. Many of them cited a lessening of involvement as the reason for their decrease in stress. "He has moved and someone else is dealing with it." Another parent credited a decrease in stress to the fact that she realized that "I couldn't do everything on my own. I got help from agencies which has been wonderful."

### Rejection of Advocacy, Negative Outcome

This quadrant contained the fewest statements in the matrix. A thematic analysis of the statements relating the rejection of advocacy to increased stress and decreased quality of life revealed the following themes:

#### (1) Hopelessness about the Future

While letting go of advocacy regarding events in the past was related to positive outcomes, giving up on the future was related to negative outcomes. When asked about future issues such as the sexuality of their child, work placements, and long-term planning for a time when the parents would no longer be able to care for their child, many parents reported rejecting advocacy, feelings of hopelessness, and increases in stress. "I'm not coping with it. That is why I have so much stress. The older she gets, the worse it gets." Another parent said, "I think he is going to have problems in the future. This is why we have pulled back, so that he could be independent. I don't know how he'll survive it."

#### (2) Giving up on Professionals and Services

Comments in this quadrant reflected a sense of "giving up" on receiving services and help from professionals. Some parents had stopped seeking services for their children, feeling that the professionals involved had created more stress than they were worth. "My life was in their hands and they didn't find an answer for me. I left feeling very down." One parent reported that she had

pulled her child out of school. “I just don’t bother sending her. Because I got fed up.”

### (3) Feelings of Guilt and Fear

Other parents commented that a lack of participation in advocacy was related to feelings of guilt and fear. “I feel pulled in every direction and guilty if I take time for myself when I could be doing something for my daughter.” Another parent made a very poignant comment about the pressure she feels to be an advocate for her child: “I feel like if I don’t participate I’ll be denied.”

### Factors

An examination of the major themes in the process outcome matrix revealed that some themes in different quadrants were related. In order to simplify the explanation of factors relating advocacy to stress and quality of life, themes with corresponding components were grouped together as major factors. This was achieved through a re-examination of the recurring regularities representing patterns (Guba, 1978). Each factor was present in more than one quadrant, and the expression of the factor determined the direction of the relationship between advocacy and stress and quality of life. Six factors were identified containing two or more of the themes. The first factor related to the parent’s perception of the role that advocacy played in the parents’ lives. This factor contained two themes, advocacy as a coping strategy, leading to positive outcomes, and advocacy as a challenge, leading to negative outcomes. The second factor concerned the outcome of advocacy. The themes of effecting positive change, becoming informed, educating others, and obtaining services related to positive outcomes. Coming up against brick walls was an outcome of advocacy leading to negative outcomes. Choosing not to advocate because it is a waste of time to try to convince people who won’t listen represented a rejection of advocacy and led to positive outcomes. The third factor, the role of professionals in

the relationship between advocacy and stress and quality of life emerged in all four quadrants of the matrix. When the role of professionals was collaborative, advocacy led to positive outcomes. Negative reactions to advocacy by professionals led to negative outcomes. When parents reported rejecting advocacy, pulling back from involvement and letting professionals take over led to positive outcomes, and giving up on professionals and services led to negative outcomes. The fourth factor, the focus of advocacy concerned whether the parents are making plans for the future, leading to positive outcomes, making efforts not to dwell on the past, leading to negative outcomes, and a sense of hopelessness regarding the future, reflecting a rejection of advocacy leading to negative outcomes. The fifth factor, the effect of advocacy on parents personal lives was composed of themes of obtaining support from others, leading to positive outcomes, accomplishing advocacy only at the expense of one's personal life and advocacy involves a lot of legwork and an overload of responsibilities, leading to negative outcomes, and pulling back from advocacy in order to take time for a personal life, reflecting a rejection of advocacy leading to positive outcomes. The sixth factor, emotional issues, also played an important role in the relationship between advocacy and stress and quality of life. This factor consisted of themes of advocacy increasing feelings of confidence and empowerment, leading to positive outcomes, personal feelings making it difficult to advocate, leading to negative outcomes, and feelings of guilt and fear of not advocating, reflecting a rejection of advocacy leading to negative outcomes. This analysis is summarized in Table 2.

### Discussion

An examination of the process-outcome matrix reveals that the relationship between advocacy and stress and quality of life is not straightforward. The participants in this study

Table 2.

**Summary of Factors Influencing the Relationship between Advocacy, Stress and Quality of Life**

<b>Quadrants</b>				
Factors	1	2	3	4
The Role of Advocacy	Advocacy is a Coping Strategy	Advocacy is a Challenge	None	None
The Outcome of Advocacy	Effecting Positive Change Becoming Informed Educating Others Obtaining Services	Coming up Against Brick Walls	It is a Waste of Time to Try to Convince People Who Don't Listen	None
The Role of Professionals	Cooperation with Professionals	Professionals React Negatively	Pulling Back from Involvement and Letting Others take Over	Giving Up on Professionals and Services
The Focus of Advocacy	Plans for the Future	None	Don't dwell on the Past	Hopelessness about the Future
Effect on Personal Life	Obtaining Support	Expense of one's Personal Life A lot of Legwork and an Overload of Responsibilities	Taking Time for a Personal Life	None
Emotional Issues	Advocacy Increases Feelings of Confidence and Empowerment	Personal Feelings Make it Difficult to Advocate	None	Feelings of Guilt and Fear

**Note.** 1 = Use of Advocacy, Positive Outcome, 2 = Use of Advocacy, Negative Outcome, 3 = Rejection of Advocacy, Positive Outcome, 4 = Rejection of Advocacy, Negative Outcome.

perceive advocacy to be related to both positive and negative outcomes regarding stress and quality of life. An analysis of the themes which emerged in this analysis and a comparison of the four quadrants of the matrix indicate that the relationship between advocacy and stress depends on the expression of a number of factors. These factors include (1) the parent's perception of the role of advocacy, (2) the outcome of the advocacy actions, (3) the relationship with professionals, (4) the focus of the advocacy efforts, (5) the effect on the parent's personal life, and (6) the parent's personal feelings regarding their experiences as a parent of a child with special needs. These factors are described in further detail below.

### The Role of Advocacy

Whether advocacy was related to positive or negative outcomes depended on the role that advocacy played in parents' lives. Advocacy can be viewed by parents as a coping strategy, that is, a method of dealing with challenging situations and obtaining a desired outcome for their child with special needs. When advocacy is perceived as a coping strategy, the parent employs advocacy to meet challenges, and the reduction of stress is related to the successes achieved through his/her efforts. In other cases, parents viewed advocacy as a challenge in and of itself. The efforts involved in advocating for their child are related to increased stress. This overall theme suggests that, in order for advocacy to be helpful to parents, they must perceive it as a strategy, rather than a hurdle.

### The Outcome of Advocacy

The outcome of an individual's effort to advocate, both within his/herself and on the community, also emerges as an important factor in the relationship between advocacy and stress and quality of life. When advocacy actions result in positive changes made in the community,

parents feel favourably about the effect of their efforts on their own levels of stress and their family's quality of life. Advocacy can be very effective in creating a more positive environment in the community through parents' education of friends and neighbours and the promotion of a more inclusive environment for individuals with developmental disabilities. Advocacy, however, is not always met with success, and many parents reported feelings of frustration and anger when their efforts were not effective in this regard. Parents' feelings that they were coming up against brick walls, achieving few successes through their efforts, were related to increased stress and decreased quality of life. Some parents, however, rejected the use of advocacy and reported that they felt favourably about the outcome. Parents reported circumstances when they felt that it would be a waste of their time to try to educate people who wouldn't listen, and make changes in situations in which the "powers that be" were satisfied with the status quo and not open to any suggestions for change. In summary, advocacy is met with positive outcomes only when the resulting changes within themselves and their community are apparent. When positive changes are unlikely to occur, it may be more beneficial for parents to refrain from advocating. Advocacy that does not result in positive change can be detrimental to parents' well-being.

### The Role of Professionals

The empowerment model of family service delivery advances the notion of parents and professionals as partners in the fight for improvements in the life of people with disabilities. When parents viewed professionals as cooperative partners in their efforts to advocate on behalf of their children, the use of advocacy was related to decreased stress and increased quality of life. However, parents also found that professionals could react negatively to advocacy. While some professionals ignored parents' efforts to educate them on their child's needs, others reacted in a

defensive manner. Understandably, a negative reaction from professionals to advocacy was met with increased stress and decreased quality of life for parents. Giving up on professionals and services emerged as a theme in the quadrant relating a rejection of advocacy to a negative outcome. Many parents felt that the adversarial nature of professionals and service providers was a challenge too great to overcome. These parents gave up on advocating for these services. They avoided trips to the emergency room, did not bring their children to the doctor, and missed out on services which might have been helpful to them. In this situation, parents did not advocate due to a feeling that they had been failed by professionals and services. However, some parents felt a great deal of confidence in professionals and service workers, and letting go of the advocacy role was related to positive outcomes in relation to stress and well-being. Parents who felt comfortable with the decisions made by professionals and service providers felt that they were able to relax their own level of advocacy and let others take over the role. In sum, the reaction of professionals is critical to parents' perceptions of the relationship of advocacy to stress and quality of life. Cooperation and partnership is the preferred relationship. When this is not the case, the outcome can be increased stress, or a decision to withdraw from the use of advocacy, at the cost of contact with services and professionals that may be beneficial. However, when parents have a strong sense of confidence in the professionals and services with which they are involved, a rejection of advocacy may be related to decreased stress and increased quality of life.

### The Focus of Advocacy

The focus of advocacy is crucial to the outcome. Advocacy was related to positive outcomes when the advocacy was focused on planning for the future. Having a goal and creating a plan allowed parents to feel successful about their efforts and confident about their children's

future. When the central issue concerned their child's future, a rejection of advocacy was related to feelings of hopelessness and a lack of knowledge about where to go for help. Parents who chose to ignore and not take the time to advocate in regards to their concerns about the future reported feelings of stress and a decreased quality of life. A rejection of advocacy was related to decreased stress and increased quality of life when the issue in question dealt with challenges that parents had faced in the past, such as the diagnosis of their child and their feelings about the cause of their child's disability. "Not dwelling on the past" was an important factor in the link between letting go of advocacy and positive outcomes. In summary, it is helpful for parents to focus advocacy efforts on future challenges and not helpful for them to focus their attention on issues that were of concern in the past. Ignoring upcoming challenges is stressful for parents, and is deleterious to parents' sense of well-being.

### The Effect on Personal Life

While many parents of non-disabled children would argue that it is difficult to maintain a personal life when raising children, the situation seems to be especially challenging for parents of children with developmental disabilities. Many parents commented that their efforts to advocate for their child with special needs were rendered at the expense of personal friendships, romantic relationships, and personal achievements in their career. In accordance with the notion that the cost of advocacy is a personal life, the rejection of advocacy led to positive outcomes in regard to parents taking their personal life back. Their decision to advocate less was related to efforts to maintain friendships, initiate relationships, and explore their own interests. However, advocacy was related to decreased stress and increased quality of life when participation in advocacy activities enabled parents to obtain the support and encouragement of other parents of children

with similar disabilities.

### Emotional Issues

It is important to consider parents' personal feelings regarding their experiences raising a child with special needs when examining the relationship between advocacy and stress and quality of life. Advocacy was related to positive outcomes when efforts enhanced parents' feelings of confidence and empowerment. However, sometimes parents' personal feelings about their experiences raising a child with special needs made it stressful for them to be involved in advocacy. Advocacy was related to negative outcomes when parents felt sadness regarding their child's condition. Choosing not to engage in advocacy was related to negative outcomes when that decision resulted in feelings of guilt for not "doing more" for their child and fear that they would be denied services.

The results indicate that parents experience advocacy in a manner that is consistent with the key components of the empowerment model as they are described by Dempsey and Foreman (1997). Advocacy that was related to positive outcomes consisted of themes relating to self-efficacy, a sense of partnership and collaboration with professionals, an increased sense of control related to planning for their children's future, an increased understanding of the environment through self-education, personal action resulting in positive environmental change, and increased access to resources. These results speak highly of the effective implementation of the empowerment model of family service delivery in Thunder Bay. Themes relating a rejection of advocacy to positive outcomes indicate that parents are being supported in their efforts to meet personal needs in making choices regarding the times to advocate, and the times when advocating

would not be beneficial to their quality of life.

While these results indicate that advocacy is beneficial for parents, it would be premature to conclude that the empowerment model of family service delivery is necessarily being implemented in a manner designed to encourage parents to engage in advocacy-related behaviours. The results of this study were consistent with the sense of ambivalence expressed by other researchers who have studied the concepts of advocacy and empowerment. Consistent with the results of analyses by Scorgie, Wilgosh, and McDonald (1996) and Cunconan-Lahr and Brotherson (1996), parents in this study reported feeling burdened by the responsibilities placed on them by professionals. Parents also found that emotions of sadness and frustration often made it difficult to advocate on behalf of their child with special needs. Nelson, Howard, and McLaughlin (1993) suggested a number of difficulties relating to the newness of the empowerment model. Consistent with their discussion of the possible problems of advocacy, parents in this study reported negative reactions from professionals, a strain on personal resources including time, energy, and the maintenance of a personal life, and feelings of guilt and fear when unable to meet the expectations of collaboration.

The empowerment model of service delivery encourages parental advocacy in its quest “to bring information, knowledge, skills and access to resources to families so that they may gain greater power over their own lives” (Dempsey, 1996, p. 7). The results of this study indicate that, in many respects, this noble goal is being achieved. However, as intuitively appealing as the concept of advocacy is, there is evidence that it is not always a positive experience for parents. When the services are not being delivered in a manner consistent with the empowerment model, efforts by parents’ to advocate for their families may result in feelings of anger, frustration, and

increased stress. The results of this study imply the need for improving the ability of professionals to provide services in a manner more consistent with the ideals of the empowerment model, enabling advocacy to be met more often with successful outcomes.

Empowerment is conceptualized as an outcome of service delivery, but it is also important to consider the process of empowerment. Parents cannot be expected to be equal collaborators with professionals at all stages of the empowerment process. In order for professionals to provide the best services to parents, professionals must maintain an awareness of the parents' emotions, abilities, and resources in order to allow parents to determine the degree to which they are able to participate in the delivery of services for their child. Dempsey and Foreman (1997) write:

The most problematic current issue for empowerment theory to deal with is the issue of whether empowerment can be influenced by staff practices and support. While the orientation and policies of disability services are influenced by philosophical beliefs such as normalization, a philosophical belief such as empowerment may not be enough to sustain an empowering orientation. If future research is able to demonstrate a causal relationship between enabling practices and empowerment, then service providers will have access to a set of demonstrably effective principles of support, and empowerment may develop as a valid psychological construct. (p. 300)

While the results of this study suggest that advocacy is related to positive outcomes when the key concepts of empowerment are present, they also indicate that the maintenance of a philosophical orientation toward empowerment does not imply that an outcome of empowerment is certain.

Although this study provides some insight into the factors which influence the relationship between advocacy and stress and quality of life, the limitations of this study must be considered.

This study involves relationships, not causes. Although the use of the process-outcome matrix permits insight regarding parents' perceptions of a causal relationship between the variables of interest, these cannot be considered as anything more than hypotheses. It is entirely possible that a reciprocal relationship is occurring. Factors such as the outcome of advocacy and the role of professionals may mediate a causal relationship between advocacy and stress and quality of life. The resulting feelings of stress and quality of life may influence parents' decisions regarding how and when they will use their abilities to advocate in the future. A well-designed experiment involving the implementation of advocacy training may indicate whether enhancing the advocacy strategies of parents will impact levels of stress and quality of life. It may also be valuable to train professionals to regard parents as collaborators in an effort to improve the sense of partnership on both sides. Research addressing the issue of the implementation of the goals and ideals of the empowerment model would be beneficial to an understanding of the degree to which these ideals are present in the day-to-day delivery of services.

The fourth criterion of completeness outlined by Guba (1978), involving the validation of the themes by the participants, was not examined for this study. This is a limitation which will be remedied shortly. Consistent with the empowering orientation of qualitative methodology, participants in this study will be given an opportunity to hear the results, and to provide input regarding the degree to which they agree or disagree with the findings. This aspect of the study will be included in a manuscript that is currently being prepared for publication.

The present study demonstrates the value of using qualitative methodology to uncover parents' perceptions of the role of advocacy in their lives, and its relationship to stress and quality of life. The role of advocacy represents a state of ambivalence which is best understood through

the words of those involved. The results indicate that the relationship between advocacy and stress and quality of life is highly dependent on the context of the services with which parents are involved. Methods of qualitative inquiry are a recommended technique for uncovering the richness of the context in which data is obtained. The philosophy of empowerment impels professionals and researchers to afford respect to the ability of individuals to understand and communicate the important components of their experience. The open-ended nature of the FSSQ allowed parents to expand on issues that they felt were crucial to an understanding of their experiences.

In summary, the results of this analysis indicate that the relationship between advocacy and stress and quality of life can be both positive and negative, depending on a number of factors. Whether advocacy is related to positive or negative outcomes is dependent on role of advocacy, the outcome of advocacy, the role of professionals, the focus of advocacy, the effect of advocacy on the parent's personal life, and the parent's own emotional issues. Although this study does indicate that advocacy is beneficial to parents when the components of empowerment are present in the delivery of services, it also indicates that advocacy in an absence of services delivered in a manner consistent with an empowerment orientation can be deleterious to family life. As an empowerment ideology pervades the delivery of services and advocacy becomes a necessity to parents of children with developmental disabilities, researchers and professionals must be aware that new roles for parents bring new challenges, as well as new successes.

## References

- Balcazar, F. E., Keys, C. B., Bertram, J. F., & Rizzo, T. (1996). Advocate development in the field of developmental disabilities: A data based conceptual model. Mental Retardation, *34*, 341-351.
- Beckman, P. J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. American Journal on Mental Retardation, *95*, 585-595.
- Cunconan-Lahr, R., & Brotherson, M. J. (1996). Advocacy in disability policy: Parents and consumers as advocates. Mental Retardation, *34*, 352-358.
- Cullen, J. C., MacLeod, J. A., Williams, P. D., & Williams, A. R. (1991). Coping, satisfaction, and the life cycle in families with mentally retarded persons. Issues in Comprehensive Pediatric Nursing, *14*, 193-207.
- Dempsey, I. (1996). Facilitating empowerment in families with a member with a disability. Developmental Disabilities Bulletin, *24*, 1-19.
- Dempsey, I., & Foreman, P. (1997). Toward a clarification of empowerment as an outcome of disability service provision. International Journal of Disability, Development and Education, *44*, 287-303.
- Dyson, L. (1991). Families of young children with handicaps: Parental stress and family functioning. American Journal on Mental Retardation, *95*, 623-629.
- Dyson, L. (1993). Response to the presence of a child with disabilities: Parental stress and family functioning over time. American Journal on Mental Retardation, *98*, 207-218.

Flynt, S. W., & Wood, T. A. (1989). Stress and coping of mothers of children with moderate mental retardation. American Journal of Mental Retardation, *94*, 278-283.

Flynt, S. W., Wood, T. A., & Scott, R. L. (1992). Social support of mothers of children with mental retardation. Mental Retardation, *4*, 233-236.

Frey, K. S., Greenberg, M. T., & Fewell, R. R. (1989) Stress and coping among parents of handicapped children: A multidimensional approach. American Journal on Mental Retardation, *98*, 207-218.

Gallimore, R., Weisner, T. S., Kaufman, S. Z., & Bernheimer, L. P. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed children. American Journal on Mental Retardation, *94*, 216-230.

Guba, E. G. (1978) Toward a methodology of naturalistic inquiry in educational evaluation. CSE Monograph Series in Evaluation, *8*.

Hixson, D. D., Stoff, E., & White, P. H. (1992). Parents of children with chronic health impairments: A new approach to advocacy training. Children's Health Care, *21*, 111-115.

Herman, S. E., & Thompson, L. (1995). Families' perceptions of their resources for caring for children with developmental disabilities. Mental Retardation, *33*, 73-83.

Intagliata, J., & Doyle, N. (1984). Enhancing social support for parents of developmentally disabled children: Training in interpersonal problem solving skills. Mental Retardation, *22*, 4-11.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. American Journal on Mental Retardation, *92*, 184-192.

Lord, J., & Hutchison, P. (1993). The process of empowerment: Implications for theory and practice. Canadian Journal of Community Mental Health, 12, 5-22.

McCubbin, H. L., & Thompson, A. I., & McCubbin, M. A. (1996) Family Assessment: Resiliency, Coping, and Adaptation. Madison: University of Wisconsin-Madison.

McKinney, B., & Peterson, R. (1987). Predictors of Stress in parents of developmentally disabled children. Journal of Pediatric Psychology, 12, 133-150.

Minnes, P. (1988). Family resources and stress associated with having a mentally retarded child. American Journal on Mental Retardation, 92, 184-192.

Minnes, P., & Nachshen, J. S. (1998). The Family Stress and Support Questionnaire: Focusing on the needs of parents. Journal on Developmental Disabilities, 5, 67-76.

Mitchell, P. (1997). The impact of self-advocacy on families. Disability and Society, 12, 43-56.

McAnaney, K. (1990) How did I get this tough? Fighting for your child's rights. Exceptional Parent, 20-22.

Munro, J. D. (1991). Training families in the "step approach model" for effective advocacy. Canada's Mental Health, 1-6.

Nachshen, J. S. (1996). Parental stress in families of children with developmental disabilities: A pilot study using the Family Stress and Support Questionnaire. Unpublished Bachelor of Arts thesis, Queen's University, Kingston, Canada.

Nachshen, J. S., & Minnes, P. (1997, April). Parents' feelings about their experiences raising a child with developmental disabilities: Preliminary data from the Family Stress and Support Questionnaire. Paper presented at the annual meeting of the Ontario Association on Developmental Disabilities, Kitchener, Ontario.

Nelson, D., Howard, V. F., & McLaughlin, T. F. (1993). Empowering parents to become advocates for their own children with disabilities. B. C. Journal of Special Education, *17*, 62-72.

Patton, M. Q. (1990) Qualitative Evaluation and Research Methods. (2nd ed.). California: Sage Publications.

Scorgie, K., Wilgosh, L., & McDonald, L. (1996). A qualitative study of managing life when a child has a disability. Developmental Disabilities Bulletin, *24*, 68-90.

Shulz, A. J., Israel, B. A., Zimmerman, M. A., & Checkoway, B. N. (1995). Empowerment as a multi-level construct: Perceived control at the individual, organizational, and community levels. Health Education Research: Theory and Practice, *10*, 309-327.

Wehemeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. American Journal on Mental Retardation, *100*, 632-642.

Wilton, K., & Renaut, J. (1986). Stress levels in families with intellectually handicapped preschool children and families with nonhandicapped preschool children. Journal of Mental Deficiency Research, *30*, 163-169.

Zimmerman, M. A. (1995). Psychological empowerment: Issues and illustrations. American Journal of Community Psychology, *23*, 581-599.

Zimmerman, M. A., Israel, B. A., Shulz, A., & Checkoway, B. (1992). Further explorations in empowerment theory: An empirical analysis of psychological empowerment. American Journal of Community Psychology, 20, 707-726.

Zirpoli, T. J., Wieck, C., Hancox, D., & Skarnulis, E. R. (1994). Partners in Policymaking: The first five years. Mental Retardation, 32, 422-425.

## General Information

Date: \_\_\_\_\_

Name: \_\_\_\_\_

Age: \_\_\_\_\_ Gender: \_\_\_\_\_

Education (highest grade or year completed): \_\_\_\_\_

Type of Employment: \_\_\_\_\_

Marital Status: 1) Single

2) Married Date: \_\_\_\_\_

3) Separated Date: \_\_\_\_\_

4) Divorced Date: \_\_\_\_\_

5) Remarried Date: \_\_\_\_\_

6) Widowed/Widowed Date: \_\_\_\_\_

Your relationship to the person with DD: \_\_\_\_\_

Age of person with DD: \_\_\_\_\_ Gender of person with DD: \_\_\_\_\_

Type of disability: \_\_\_\_\_

Level of disability: mild moderate severe

Does the person with DD live with you? \_\_\_\_\_ How long has s/he lived with you? \_\_\_\_\_

If no: a) Where does the person with DD live? \_\_\_\_\_

b) How long has s/he lived there? \_\_\_\_\_

c) Did the child with DD live with you before? \_\_\_\_\_

If yes, for how long? \_\_\_\_\_

Who else lives in your home?

Relationship

Age

Gender

The Family Stress and Support Questionnaire

**How stressful are the following issues for you now?**

Not Stressful

Moderately Stressful

Extremely stressful

0

1

2

3

4

1. **Diagnosis of your child as having a developmental disability.** \_\_\_\_\_
2. **Seeking a second opinion.** \_\_\_\_\_
3. **Explaining to others about your child's disability.** \_\_\_\_\_
4. **Your feelings about the cause of your child's disability.** \_\_\_\_\_
5. **Dealing with friends/family/people in the neighbourhood on a day-to-day basis.** \_\_\_\_\_
6. **Dealing with doctors and other allied health professionals.** \_\_\_\_\_
7. **Dealing with legal professionals.** \_\_\_\_\_
8. **Dealing with your child's teachers and the educational system.** \_\_\_\_\_
9. **Creating and/or finding opportunities for your child to make friends and participate in activities.** \_\_\_\_\_
10. **Choosing the best level of integration for your child.** \_\_\_\_\_
11. **Making the decision concerning accommodation in the home or in the community.** \_\_\_\_\_
12. **Meeting the needs of your other children.** \_\_\_\_\_
13. **Meeting your own personal needs.** \_\_\_\_\_
14. **Meeting the needs of your spouse.** \_\_\_\_\_
15. **Maintaining satisfying friendships for yourself.** \_\_\_\_\_
16. **Dealing with your child's sexuality.** \_\_\_\_\_
17. **Work placements or employment for your child.** \_\_\_\_\_
18. **Long-term planning for accommodation for your child.** \_\_\_\_\_
19. **Planning for wills, trusts and guardianships.** \_\_\_\_\_
20. **Planning for emotional and social support for your child.** \_\_\_\_\_
21. **Transportation.** \_\_\_\_\_
22. **Day to day assistance with care of child.** \_\_\_\_\_
23. **Time apart from your child.** \_\_\_\_\_
24. **Dealing with financial issues.** \_\_\_\_\_

# 1. The diagnosis of your child as having a developmental disability.

A) Please describe the circumstances under which you discovered that your child had a developmental disability.

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

- |                           |                    |           |                    |
|---------------------------|--------------------|-----------|--------------------|
| I) over the last 5 years? | Increase in stress | No change | Decrease in stress |
| II) in the last year?     | Increase in stress | No change | Decrease in stress |

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 2. Seeking a second opinion.

A) Please describe your experiences with this issue.

How have you tried to cope with this challenge? Why did you choose this strategy ? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

### 3.Explaining to others about your child's disability.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy ? Has this been helpful?

B)Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D)-What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

#### **4. Your feelings about the cause of your child's disability.**

A) Please describe your thoughts on this issue.

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) -What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

**5. Dealing with friends / family / people in the neighbourhood on a day - to - day basis.**

A)What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B)Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D)-What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

**A)What successes have you had and how did you achieve them?**

**What challenges have you faced in this particular issue?**

**How have you tried to cope with this challenge? Why did you choose this strategy ? Has this been helpful?**

**B)Has the stress related to this issues changed:**

**I) over the last 5 years?      Increase in stress      No change      Decrease in stress**

**II) in the last year?      Increase in stress      No change      Decrease in stress**

**C) If changes in stress have occurred, why?**

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

**D)-What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?**

## 7. Dealing with legal professionals.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issue changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) - What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 8. Dealing with your child's teachers and the educational system.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) - What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

**9. Creating and / or finding opportunities for your child to make friends and participate in activities.**

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?	Increase in stress	No change	Decrease in stress
II) in the last year?	Increase in stress	No change	Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 10. Choosing the best level of integration for your child.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?	Increase in stress	No change	Decrease in stress
II) in the last year?	Increase in stress	No change	Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) -What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?!

# 11. Making the decision concerning accommodation in the home or in the community.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) - What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 12. Meeting the needs of your other children.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issue changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) -What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

### **13. Meeting your own personal needs.**

**A)What successes have you had and how did you achieve them?**

**What challenges have you faced in this particular issue?**

**How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?**

**B)Has the stress related to this issues changed:**

**I) over the last 5 years?      Increase in stress      No change      Decrease in stress**

**II) in the last year?      Increase in stress      No change      Decrease in stress**

**C) If changes in stress have occurred, why?**

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

**D)-What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?**

#### 14. Meeting the needs of your spouse / partner.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issue changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) - What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 15. Maintaining satisfying friendships for yourself.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) -What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 16. Dealing with you child's sexuality issues.

A)What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy ? Has this been helpful?

B)Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D)-What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 17. Work placements or employment for your child.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issue changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 18. Long - term planning for your child's accommodation

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issue changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) - What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## 19. Planning wills, trusts and guardianships.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issue changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) - What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

**20. Long term planning for the emotional and social support of your child.**

(A)What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy ? Has this been helpful?

B)Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D)-What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## **21. Transportation.**

**A) What successes have you had and how did you achieve them?**

**What challenges have you faced in this particular issue?**

**How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?**

**B) Has the stress related to this issues changed:**

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

**C) If changes in stress have occurred, why?**

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

**D) -What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?**

## 22. Day-to-day assistance with care of child.

A) What successes have you had and how did you achieve them?

What challenges have you faced in this particular issue?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) -What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

**23. Time apart from your child.**

A) When have you spent time apart from your child?

B) Was this time apart planned or a result of circumstances (e.g. health, family issues)?

C) What successes have you had and how did you achieve them?

How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?

B) Has the stress related to this issues changed:

I) over the last 5 years?      Increase in stress      No change      Decrease in stress

II) in the last year?      Increase in stress      No change      Decrease in stress

C) If changes in stress have occurred, why?

1. \_\_\_\_\_ Behaviour change in child
2. \_\_\_\_\_ Change in child's health
3. \_\_\_\_\_ Change in caregiver's health
4. \_\_\_\_\_ Change in family situation (death, separation)
5. \_\_\_\_\_ Other \_\_\_\_\_

D) -What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?

## **24. Dealing with financial issues.**

**A) What successes have you had and how did you achieve them?**

**What challenges have you faced in this particular issue?**

**How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?**

**B) Has the stress related to this issue changed:**

**I) over the last 5 years?      Increase in stress      No change      Decrease in stress**

**II) in the last year?      Increase in stress      No change      Decrease in stress**

**C) If changes in stress have occurred, why?**

- 1. \_\_\_\_\_ Behaviour change in child**
- 2. \_\_\_\_\_ Change in child's health**
- 3. \_\_\_\_\_ Change in caregiver's health**
- 4. \_\_\_\_\_ Change in family situation (death, separation)**
- 5. \_\_\_\_\_ Other \_\_\_\_\_**

**D) -What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?**